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Construction of meanings during life-limiting illnesses and its impacts on palliative care: ethnographic study in an African context

Short title: Meaning-making in cancer and palliation in an African context

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Objective: knowledge about how people make meaning in cancer, palliative and end of life care is particularly lacking in Africa, yet it can provide insights into strategies for improving palliative care (PC). This study explored ways in which cancer patients, their families and healthcare professionals construct meaning of their life-limiting illnesses and how this impact on provision and use of PC in a Nigerian hospital.

Methods: This ethnographic study utilised participant observation, informal conversations during observation and interviews to gather data from 39 participants, comprising service-users and healthcare professionals (HCPs) in a Nigerian hospital. Data was analysed using Spradley's framework for ethnographic data analysis.

Results: Meaning-making in life-limiting illness was predominantly rooted in belief systems. Most patients and their families, including some HCPs, perceived that cancer was caused by the devil, mystical or supernatural beings. They professed that these agents manifested in the form of either spiritual attacks or that wicked people in society used either poison or acted as witches/wizards to inflict cancer on someone. These beliefs contributed to either non-acceptance of, or late presentation for, PC by most of patients and their families, whilst some professionals depended on supernatural powers for divine intervention and tacitly supporting religious practices to achieve healing/cure.

Conclusion: Findings revealed that cultural and religious worldviews about life-limiting illnesses were used in decision-making process for PC. This, therefore, provided evidence which could improve the clinicians' cultural competence when providing PC to individuals of African descent, especially Nigerians, both in Nigerian societies and in foreign countries.

Key words: Africa**,** belief systems, behaviour, cancer, culture, meaning-making, Nigeria, oncology, palliative care, religion.

BACKGROUND

Palliative care (PC) has become an important public health issue in recent years and has been declared a universal human right [1-2]. The need for PC is rapidly increasing, yet there is significant disparity and inequality in the world-wide provision and use of PC [1,3]. To date, previous studies indicate that it has steadily improved in the more economically developed countries but has continued to be less available and under-utilised in low and middle-income countries, especially in African countries such as Nigeria [4-6]. There is a growing number of studies indicating that inadequate funding, opioid availability, policy, and education impact on PC, especially in the African context [3,7-9], but there is a paucity of research on how meaning-making in serious illnesses influences PC.

There is an extensive body of evidence that most people tend to re-define or re-negotiate meaning when they are challenged by adverse situations [10], such as cancer and other life-limiting illnesses. Religious beliefs have been used as a resource for coping and meaning-making in illness for patients with cancer and other serious illnesses [11-13]. Some authors argue that culture is also relevant at the end of life because it could influence the meaning and experience of dying and death [14]. Cultures varies concerning how people conceptualise dying [15], implying that the society within which people are enculturated strongly influences how they experience and understand dying. Notably, Powell and colleague has emphasised that research investigating meaning-making in illness and end of life care was particularly lacking in Africa[16]; this was also highlighted in a recent literature review [17]. Therefore, this qualitative study aimed to explore ways in which cancer patients, their families and healthcare professionals construct the meaning of their life-limiting illnesses and how this impact on the provision and use of PC. Given the paucity of research focusing on construction of meaning during life-limiting illnesses in Africa, in-depth information from one study site is valuable in

understanding this problem, thereby providing evidence for theory development whereby ideas can be transferred to another similar context [18]

METHODS

Design and setting

This study used a qualitative exploratory design and an ethnographic approach. This methodology is appropriate because it is recommended when access to beliefs, social interactions and behaviours are required[19]. Nigeria is a culturally diverse country with six geopolitical zones and over 250 ethnic groups[20]. South-east zone was chosen for this research due to its geographical proximity, familiarity and accessibility. A hospital located in South-Eastern Nigeria which was purposively selected because it provided organised PC services, that enabled collection of useful data.

Participants (recruitment, sample designation and size)

All 11 members of the hospital multi-professional PC team (three doctors, four nurses, a physiotherapist, two social workers and a pharmacist), 10 cancer patients, and 10 patients' relatives were initially recruited after they signed consent form to participate in the study. Following preliminary data analysis in the field, an additional eight healthcare professionals (five doctors and three nurses) from oncology department were identified and recruited because they provided additional information which enhanced deeper understanding of the emerging cultural pattern as would be expected in ethnographic research [21]. Overall, 39 participants took part in the study who were selected purposively based on the following criteria:

Healthcare professionals who

- had experiences of providing PC
- were principally involved in decision making about the care of patients with cancer

Patients who

- were living with progressive life-limiting illnesses (cancer)
- were receiving or requiring PC
- were living and assessed to have capacity to provide informed consent

Family members who

- were the main carer of the cancer patient who was receiving and/or requiring PC.

Ethical approval and considerations

Ethical approval was granted by the University of Northampton Research Ethics Committee as well as by the University of Nigeria Teaching Hospital's Research Ethics Committee with reference number: UNTH/CSA/329/OL.5. Participant information sheet was given to all the potential participants and then written consent was obtained a week prior to data collection and was followed by verbal consent at the start of each daily observation. This was important due to the long immersive nature of the study. Confidentiality was also maintained through measures which included but were not limited to, anonymised personal details of the participants, using pseudonyms during reporting of findings, keeping data in password protected computer files in keeping with principles of non-maleficence, upholding privacy and respect for autonomy.

Data collection

Participant observation and informal conversations during observation

Participant observation improves researchers' understanding of the situation and adds strength to the authenticity of the data[21]. Guided by Spradley's framework [21], descriptive, focused and selective participant observations were conducted in the PC unit and the oncology department of the studied hospital. The first author undertook the role of a nurse and adopted an observer stance as participant-as-observer because it facilitated an in-depth

understanding of the symbolic meanings of life-limiting illnesses and cultural rules for behaviour about care delivery and utilisation of PC. Participant observations were conducted eight hours daily for three days a week over 24 weeks in the seven wards, the PC outpatient clinic, PC nurses' station, the oncology outpatient's clinic and meetings between the patients' relatives and the PC team. Data gathered during participant observation were documented in field notes. Participants were also engaged in casual conversation to clarify what was observed. Overall, 576 hours of participant observation were completed from January 2017 to June 2017.

Interviews

Semi-structured in-depth face-to-face interviews were carried out with all 39 participants who were Christians. By conducting interviews, the understanding of the context and intentions behind the observed behaviour and practices was better understood as well as providing an opportunity to elicit information about what may have not been observed as Creswell[22] suggests. Firstly, descriptive questions were asked, followed by what Spradley regarded as structural questions and then contrasting questions[23], with sample in Table 1. Each interview lasted between 45 and 90 minutes and was recorded and transcribed.

Insert Table 1

Data analysis

Spradley's framework for ethnographic data analysis, which comprises domain, taxonomic, componential analysis and the discovery of cultural themes, was used to guide the analysis [21]. During domain analysis, NVivo 10 was used to organise the voluminous amounts of, what Spradley regarded as, 'include terms', and 'cover terms'. This was followed by a search for semantic relationships by constructing, what Spradley regarded as, domain analysis as shown in Table 2 below.

Insert Table 2

Secondly, taxonomic analysis was undertaken, whereby the relationships that existed within and among the cultural domains were searched and organised on the basis of a single semantic relationship to arrive at the taxonomies as shown in Figure 1 below.

Insert Figure 1

Thirdly, ‘paradigm worksheets’ were used to separate the contrasts/units of meaning from the cultural categories at the stage of componential analysis. See Table 3 for an illustration.

Insert Table 3

Finally, the relationships that existed amongst the larger set of cultural categories were examined, by grouping the categories that fitted together as subsets of single ideas, to arrive at two cultural themes; cultural beliefs about life-limiting illness and religious beliefs about life-limiting illness, as represented schematic framework (Figure 2 below).

Insert Figure 2

Rigour

Trustworthiness criteria is considered contentious in ethnography[24] thus, standards for assessing qualitative research were applied in this study. The transferability and conformability of the study findings were accomplished through explicitly documented methods and analysis[25]. Prolonged field engagement and persistent observation facilitated emic perspectives, thus enhanced study credibility. Reflexivity was also fundamental to enhancing study rigour. The first author worked as a nurse-ethnographer conducting research in a study site and with staff unfamiliar to him. This unfamiliarity helped him to maintain detachment and the critical eye required during ethnography. However, his nursing background and being born in the geopolitical region of Nigeria where the study site is

located, he inevitably possesses implicit knowledge of beliefs about death and dying. There were moments of cultural shock during observed realities, but continued reflexivity enabled him to cope with these while maintaining open-mindedness during field work. Engaging with other research team members to discuss the ongoing fieldwork and to confirm field analysis, mitigated bias, enhanced accuracy and credibility of the findings.

RESULTS

Cultural beliefs about life-limiting illness

Data from the service-users suggest dominant cultural beliefs that cancer and other life-limiting illnesses are caused by 'evil others' (wicked people in the society), perceived as mothers-in-law, grandmothers, grandfathers, neighbours, brothers, sisters and other family members or friends. Participants also perceived that a wicked person could either use poison or act as a witch or a wizard to inflict cancer on someone:

> *Our landlord is a witch. She even killed her own sisters with cancer and caused this breast lump to my sister (Interview excerpt, Patient relative 7)*

> *My grandfather is an evil man. I stepped on poison that was placed by him which caused this illness… (Interview excerpt, Patient 1)*

Although, most of the patients and their families predominantly attributed their life-limiting illnesses to 'evil others', they also perceived that it was also caused by mystical or supernatural beings believed to be manifested in form of spiritual attacks:

> *My wife nearly died four years ago but through prayer, the enemies were defeated. I think this illness is a spiritual attack (Interview excerpt, Patient relative 9)*

> *Considering the places my sister has gone for treatment, but her case was not healed whereas other people with similar cases were healed, I, therefore, believed it is a spiritual problem (Interview excerpt, Patient relative 6)*

The patients and their family caregivers defined, and interpreted life-limiting illness based on the principles and value system inherent within their culture and revealed a shared understanding when constructing meaning about serious illness, which may have been negotiated over time. Remarkably, some of the HCPs perceived meaning of cancer was also rooted in their cultural beliefs. For instance:

> *As an African man, I believe there are unseen forces everywhere pursuing people and this caused some serious illnesses such as cancer (Interview excerpt, Doctor 3)*

> *I believe that people do have spiritual attack, but I am against people believing that cancer or other terminal illnesses is a spiritual attack (Interview excerpt, Nurse 3)*

The patients, their families and some HCPs appeared to have constructed meanings of cancer and other life-limiting illnesses in line with a personalistic disease-theory system which attributes the cause of illness to intervention by agents such as supernatural forces (deities) and other human (evil persons) or non-human (evil spirits) forces[26]. Thus, they have utilised traditional or lay explanatory models in constructing their knowledge of cancer aetiology. An alternative interpretation could be that cultural meaning-making may be an unconscious attempt to suppress awareness of the potential death from cancer. It could also be a sign of holding unto false hope originating from cultural knowledge leading to constructions which lacked scientific credence. Interestingly, the data showed that patients and their families appeared to have nurtured and developed these culturally-bound beliefs when their expectations of a cure failed after attempting several treatments. Whereas, the HCPs seemed to have relied upon wider system of inherent cultural understandings (beliefs) either when they lacked understanding of the disease aetiology or when the medical interventions failed to achieve a cure. This suggests that the belief systems held by some professionals outweighed their scientific knowledge during a time of adversity. Overall, using a cultural lens to make

meaning could imply either superstitions, gaps in biomedical knowledge, or a lack of understanding of benefits that could be gained from palliation.

Impact of cultural beliefs about life-limiting illnesses on palliative care

Most of the service-users were found to have rejected palliation, pursuing curative care instead. Those already admitted for PC predominantly requested discharge because they perceived that oncology and palliative care was not working'.

> *We have tried medical but 'it is not working'. I requested for discharge because we need to go make a sacrifice to appease the gods (Interview excerpt, Patient relative 3)*

> *She frowns her face and said 'Doctor I want you to discharge us. I want to take him somewhere for traditional care as there is no improvement in his condition. I believe, he will be cured with spiritualists' interventions (Field note, F28)*

Palliative care was conceptualised as 'not working' as it did not meet their expectations for a cure. This misunderstanding of PC led to its non-acceptance. Instead, the patients and their families preferred to seek care with providers such as spiritualists, herbalists and native doctors, who provided them with psychological security or protected their sense of life preservation, consistent with their cultural beliefs. These providers were believed to be endowed with supernatural abilities to confront the activities of wicked persons, and to possess metaphysical eyes able to understand spiritual mysteries and to provide solutions to life-limiting illnesses, as portrayed by some patients and families as well as some of the HCPs. For instance, Pharmacist Lily said:

> *...'O nafu uzo'*, interpreted as *'he sees'*, *they (*spiritualists, herbalists and native doctors*) have spiritual eyes to see the causes and solution to such illnesses.*

It appears that curative care was more culturally valued and accepted in this society and this may provide insight into patients' unwingness to use PC. Although few of the service-users appeared to have accepted PC, they returned to hospitals after all other options had been exhausted:

> *I have visited several herbalists and native doctors, but the illness was not any better. Finally, I returned to this hospital as my last hope (Interview excerpt, Patient 9)*

This extract provides an understanding of why PC was used as a last resort by most of the patients and their families when other measures had failed. Thus, it provides an explanation of the observed cultural discourse for non- or late presentation of patients with life-limiting illnesses for palliation.

Religious beliefs about life-limiting illnesses

Most of the patients and their families perceived that cancer were caused by the devil but expressed a shared belief that God controlled their life and, therefore, had the ultimate power to heal their life-limiting illness:

> *This sickness is caused by the devil. I believe that Almighty God is still on the throne, he can cure me. God has control over life and everything that happen in this world… (Interview excerpt, Patient 10)*

Some HCPs also used their religious beliefs in meaning-making. For instance, Doctor 4 professed that if medicine fails, a miracle is possible:

> *Truly, I believe in Gods' miracles and that God uses us to achieve the miracles... Sometimes, when medical intervention fails, God still heals cancers*

Overall, the presupposition that the devil causes cancer suggests the use of religious knowledge in the construction of meaning, indicating seeking of solace in a supernatural

being, but it could also suggest a lack of scientific understanding of life-limiting illnesses. Since most of the service-users and some HCPs perceived that God was in control, they chose to persevere with their psychologically comforting beliefs, and hoped-for miraculous healing/cure of life-limiting illnesses by God. This is suggestive of a strategy to foster hope and/or to dispel thoughts about death and dying, while increasing commitment to their religious world views for life preservation.

Some of the HCPs suggested that these religious beliefs originated from the teachings of religious preachers such as:

> *The Lord said that none of you shall be sick*
>
> *Healing is your birthright*
>
> *God is in the business of performing miracle today*
>
> *(Interview excerpt, Doctor 2)*

> *You cannot die of cancer*
>
> *Back to sender (a phrase which culturally symbolises a command for the illness to return to the evil person perceived to have sent it)*
>
> *God is a healer*
>
> *(Interview excerpt, Nurse 3)*

This gives the impression that religious preachers propagated religious values that consider dying of cancer as a taboo and fostered hope in people about divine miracles and healing, thereby encouraging the pursuit of any means to stay alive. Plausibly, any patient and/or family member that believed in these religious teachings would be likely to be in conflict with the decision to accept PC.

Impact of religious beliefs about life-limiting illnesses on palliative care

Most of the service-users were found to have rejected medical advice for PC and preferred to engage solely in religious rituals, such as prayer, whilst others sought care in religious places, such as churches and prayer houses:

> *In a situation that people are told about their illness, they will refuse medical advice and rather prefer to visit the church to pray it out. This is not bad. Laugh! I am an African person too (Interview excerpt, physiotherapist Zoe)*

> *When I was told that it is cancer, I went to the church to pray. I have trust in God and believed that God will cure me (Interview excerpt, Patient 4)*

Decision making about the use of PC appeared to be influenced by the service-users' religious beliefs, which were founded on religious teachings. These beliefs contributed to either non-acceptance of, or late presentation for, PC by most of the patients and their families. Since most of the religious worshippers tended to accept and follow the advice from their religious preacher, they dismissed the advice from the healthcare professionals:

> *I did not come to hospital when this illness started because my pastor said we will do fasting and prayer to cure it. One of the nurses advise me to attend hospital but I followed the advice of my pastor… (Interview extract, Patient 6)*

The stronger trusting relationship between service-users and the pastors could be rooted in the premise that the pastors were believed to possess spiritual powers for the healing of cancer and other life-limiting illnesses, unlike doctors;

> *Many of the pastors claim they have spiritual and supernatural power for healing cancer and other serious illnesses (Interview excerpt, Doctor 2)*

Lastly, the service-users appeared to be deeply committed to their religious beliefs and engaged in their religious practices, even in their hospital beds. For example, it was observed that some patients and their relatives wore a religious bangle and a string of beads for counting prayers on their wrists and necks. There were also stickers of an image of a pastor on some of the patients' beds. Most of the services users, and some HCPs, seemed not to have accepted the reality of imminent death, but chose to hold onto beliefs or what could be regarded as a unique way of viewing the dying process, because it offered them psychological security.

DISCUSSION

The HCPs tended to negotiate meaning by using their cultural worldviews to form a situational or appraised meaning upon which PC would be based, when they lacked scientific rationality or biomedical understanding about the care of cancer patients. They relied on supernatural powers for divine intervention, while tacitly supporting practices such as prayers, fasting or sacrifice to achieve healing/cures, rather than focusing on the medical measures or practices that would relieve suffering, enhance the quality of life and promote a good death. This implies that refracting to lay epidemiology or understanding to inform meaning and behaviour during serious illnesses[27-29] is not limited to lay people but also applies to the professionals**.** However, provision of PC was largely based on conventional medical practices in the studied hospital, as the majority of the professionals did not subscribe to the cultural worldview.

In this current research, cultural and religious beliefs provided protection for the patients and their relatives against their death-related cognition, arising from the perceived threat to their life of their illnesses, which was in agreement with the theoretical construct of terror management theory [30-31]. Therefore, these patients and their families consistently denied the

reality of their illness, instead choosing to believe in the rationality of their worldviews, which led to formation of an expectation which did not favour positive behaviour towards the use of PC. Other previous studies have documented similar findings about strong spiritual/religious beliefs among African Americans [11, 32-33], suggesting that this way of thinking is rooted in a traditional explanatory model may likely be inherent in most of the black race, irrespective of the country where they live. Perhaps, the difference in meaning-making among people from African descent could be based on the degree of how modernisation has affected their traditional beliefs. Remarkably, faith in God about miraculous healing deterred some service-users from seeking or accepting PC in the current study, contrary to other previous research, where religious beliefs facilitated patients' acceptance of their illness and PC, based on their belief that illness is God's will and death is a passage to another life [34-35].

Furthermore, the service-users in this current study consistently expressed ideas indicative of dispelling thoughts about death, facilitated by religious preachers using words or phrases that could signify that cancer and other life-limiting illness was a taboo. In the south-western culture of Nigeria, it has been reported that dying of a life-threatening illness was regarded as a taboo [36]. The religious preachers seemed to encourage their congregants with cancer to adhere to religious rituals or to pursue other means to preserve life, while discouraging PC.

Study limitations

Given that this study was conducted in one hospital with a sample size which may not be representative of the population of patients with cancer and the professionals that provide care to such population, all the conclusions presented herein may not be generalisable in any strong sense, though the findings can be transferred to similar context due to ethnographic feature of contextualisation [37-38].

Clinical implications

This ethnography revealed a common set of cultural and religious beliefs amongst service-users and HCPs that informed the meaning system in life-limiting illness with explanation of how these impacted on provision and use of PC in the Nigerian context. Theoretically, it extends the findings that broadly mentioned that religion was an obstacle to PC in Nigeria [36,39] by clarifying how religious as well as cultural beliefs impacted on PC. This could be enlightening as it portrays how culture and religion are still powerful in influencing thinking in modern societies.

Our findings also provided evidence which clinicians around the world could use to enhance their broad understanding of meaning making in life-limiting illness and could be particularly used to enhance cultural competence while providing PC to individuals of African descent, especially Nigerians, both in Nigerian societies and in foreign countries. However, due to individual differences in belief systems that exist in the same culture because of differences in experiences and social metrics, we acknowledge that evidence about meaning systems should not be rigidly used in clinical practice to avoid stereotyping and prejudice, although the findings are still clinically relevant in providing a broad awareness and understanding of how people of African ancestry may make meaning in life-limiting illnesses, to better comprehend individual perspectives.

Finally, our findings showed that some doctors and other healthcare professionals may use their belief systems to refract their ability to ‘see’ the world and this could influence their care provision, thereby underscoring the need to make reflexive practice a gold standard in PC practice in all countries, especially Africa.

Conclusions

This study has shown that culture and religious beliefs in African context seem to be fundamental in human existence but were mostly reactivated in the circumstance of serious illness to challenge the general discourse or individuals' general orienting system and views. This has led to appraisals of life-limiting illnesses, forming situational meaning in terms of causal attributions of such illnesses. These findings are suggestive of the need for a shift from culturally-bound interpretations to scientific reasoning about cancer. This can be achieved through health education to inculcate positive re-interpretation, or reappraisal, of meanings associated with life-limiting illness and palliation, thereby promoting its utilisation. Further research is required with Muslim population, given that Nigeria is a multi-religious country with diverse religious beliefs.

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Conflict of interest: The authors have none.

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Figure 1: Sample of taxonomic analysis

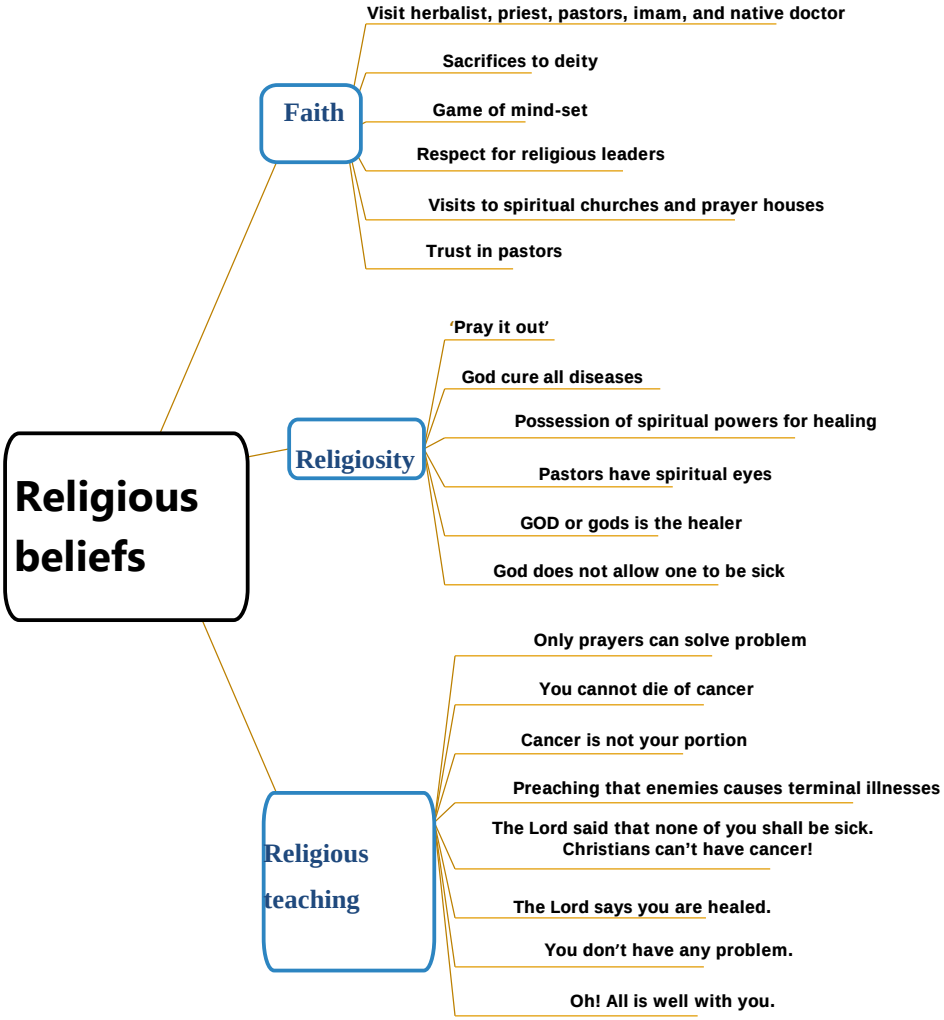

Figure 2: Cultural schema of the themes

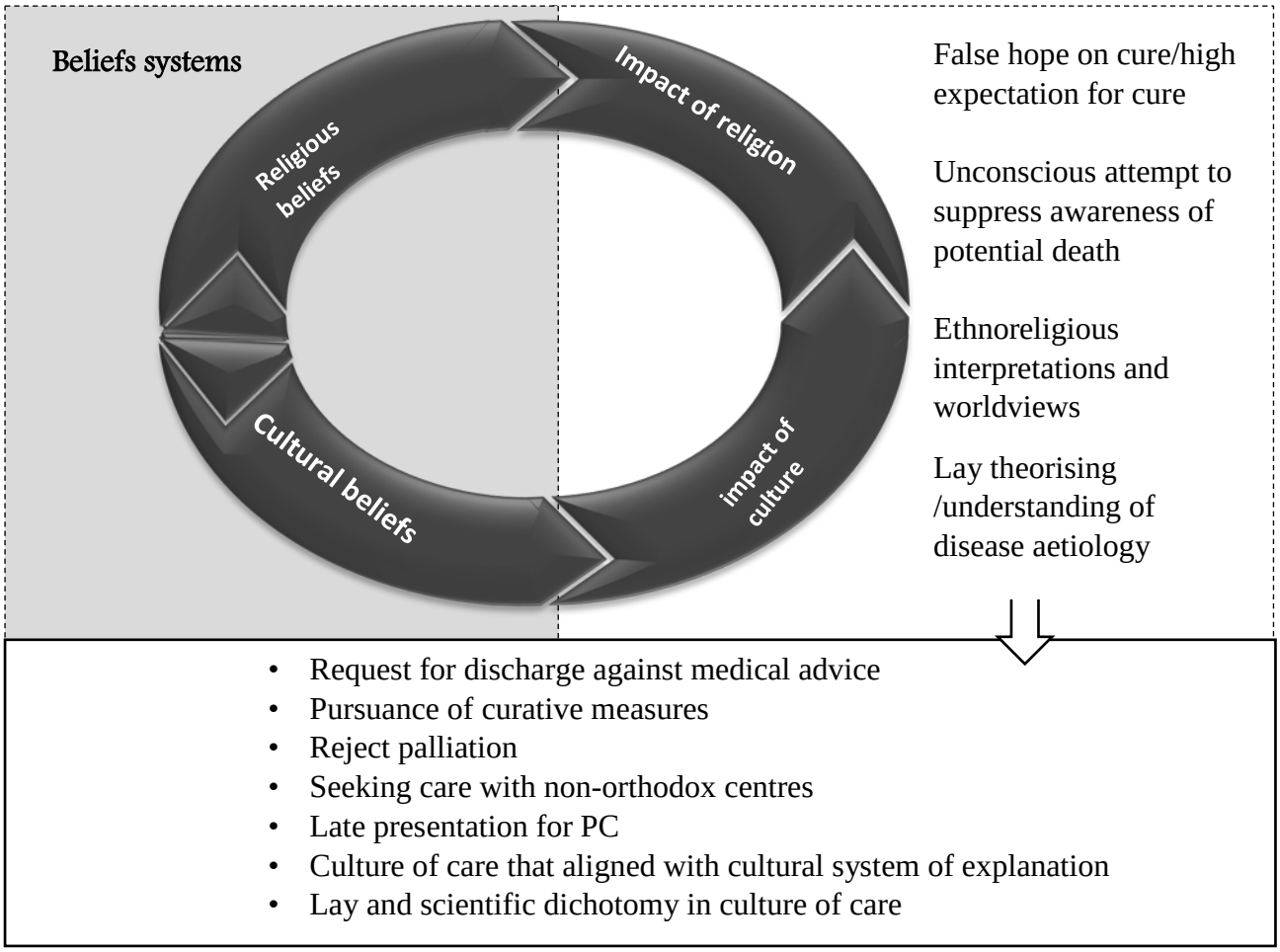

Table 1: Sample of each level question

Descriptive questions	Structural questions	Contrast questions
• What are your thoughts about this illness? • Can you tell me about the illness of your family member? • Can you tell me about the care you are providing to these patients?	Please can you tell me more about • What you believe about this illness? • The care you are receiving here? • How you perceive the care you are render to these patients?	Can you tell me the difference between care you received in other places and now you are in the hospital?

Table 2: Sample of domain analysis worksheet

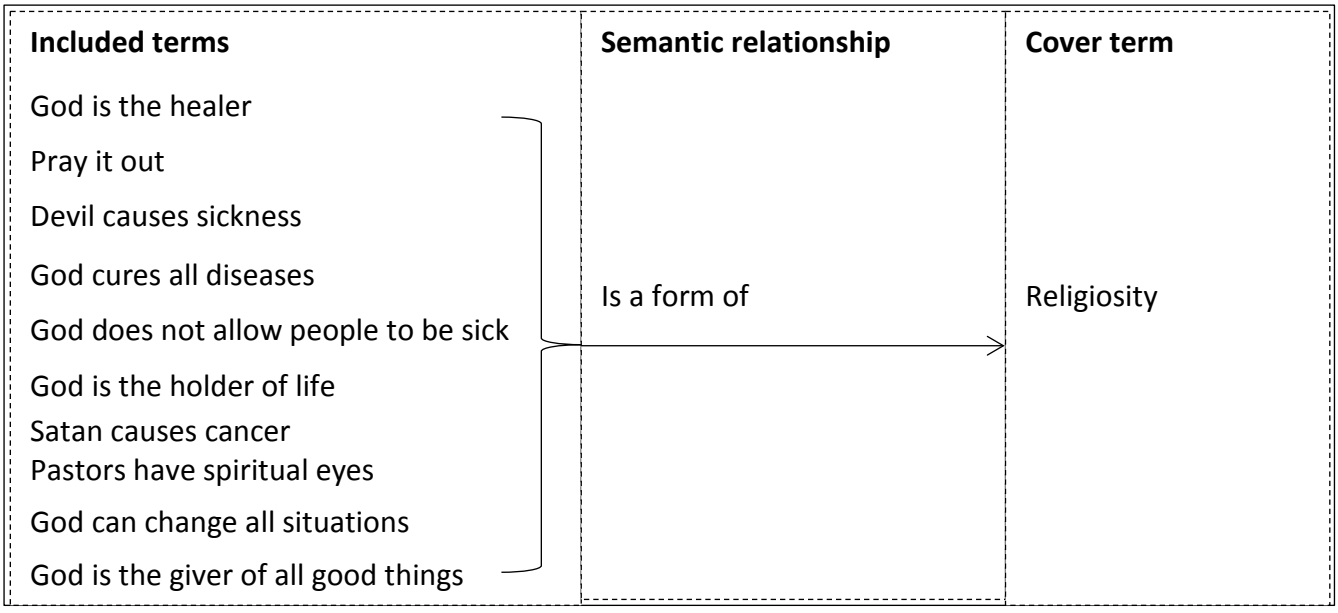

Table 3: Paradigm worksheet using cultural categories of religious beliefs

Domain (cultural category)		Dimensions of contrast	
		Evil others	Mystical/ supernatural beings
Religious belief	Terminally ill patients	Yes	Yes
	Patients families	Yes	Yes
	Healthcare providers	No	Yes